SURGICAL ETHICS CHALLENGES

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We are pleased that this month's article in the Surgical Ethical Challenges series has been contributed by a journal reader. The editors encourage the readership to submit articles on matters of surgical ethics for publishing consideration. Submissions should be of a length and format similar to papers typically appearing in Surgical Ethical Challenges over the last several years. Those considered by the editors to be of sufficient interest and good quality will be published in the *Journal of Vascular Surgery.*

To inform or not to inform: How should the surgeon proceed when the patient refuses to discuss surgical risk?

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A 67-year-old man presents with a 6.9-cm juxtarenal aneurysm that is unsuitable for endovascular stent-grafting. After a discussion in the outpatient clinic of the risk of rupture, the patient agrees that the vascular surgeon should perform an open abdominal aneurysm repair. The patient understands that this is a major operation involving an abdominal scar and that his aneurysmal aorta will be replaced with a prosthetic graft to prevent aneurysm rupture. Nevertheless, he adamantly refuses to hear about or to discuss the risks of the procedure. The patient states that he needs the repair and wishes to proceed with surgery because he believes that all his doctors think it is best for him to do so. He claims that since he will ultimately undergo the operation anyway, any discussion of risks will cause him and his family unnecessary anxiety. The patient is competent to consent to the operation and agrees to sign as many documents as needed, stating again that he does not wish to know the risks and that he will take no legal action against the surgeon or the hospital should a properly conducted operation result in a poor outcome of which the patient would normally have been informed. The hospital legal counsel confirms that medicolegally it is reasonable to proceed in this individual case. Nevertheless, the vascular surgeon has some ethical concerns. How should he proceed?

A. Proceed with surgery.

B. Agree to perform the surgery without discussing the risks with the patient, but discuss the risks with his next-of-kin (against the patient's expressed wish).

C. Accept that the patient does not want to know all the risks but insist on telling him of the major risks, particularly death and end-stage renal failure.

D. Attempt to evaluate which values are important to the patient and disclose risks accordingly.

E. Refuse to operate but refer for a second opinion.

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To consider this issue, it is necessary to first assess why risk disclosure is deemed important (legal issues aside). The generally accepted reason is that it increases patient autonomy and allows the patient to make a decision that is truly in his best interests. The reasoning behind this is that a competent individual is the best judge of his own best interests. A provisio here, however, is that where the knowledge gap is large, the individual may be less well placed than the surgeon to decide what course of action is in his or her best interests. This is the situation here: the patient does not want the information he needs to make a truly autonomous decision. In this situation, however, all are agreed that he should have the operation. The surgeons believe this is the best course of action because their superior knowledge of the risks and benefits tells them that surgery is in the patient's best medical interests. They cannot, however, truly assess whether it is in his overall best interests taking into account individual psychological and social aspects. The patient has decided that surgery is the appropriate course because he trusts his doctors.

Although risk disclosure is accepted as good practice, patient refusal or unwillingness to discuss risks does regularly occur. When the patient is competent to give valid consent and understands the aim and general nature of the

operation, as here, the dilemma centers on whether it is possible for a self-determining individual—without knowing the risks—to state that he does not want to know what the risks of surgery are. For example, if he is not aware that end-stage renal failure is a possibility, how can he autonomously state that this (and every) risk will not affect his decision to undergo surgery?

Andorno[1] writes that the right not to know is an expression of autonomy, yet recognizes the dilemma: "the main practical objection to the right not to know is that in order to decide not to receive some information, the person should previously be informed of the possibility of having a particular health risk. Now this is precisely what the individual wanted to avoid."

Respect for patient autonomy rightly has a large influence on the practice of modern medicine. Thus, if one accepts the desire not to know is truly autonomous, it is morally acceptable and even perhaps obligatory *not* to insist on informing the patient of the risks. Proceeding in the absence of risk discussion could be justified by the concept that the patient has sacrificed his autonomy in the decision process by refusing to discuss risks—in fact, he has autonomously sacrificed his autonomy!—and has accepted that his treatment should be planned according to the principle of beneficence. Provided that the proposed surgery is held in good faith to be in his best interests, this is a morally acceptable way forward. Some may suggest this has paternalistic overtones, but accusations of paternalism are unjustified because it is the patient who has sacrificed his autonomy in this one area rather than the surgeon overriding his autonomy.

Furthermore, issues of privacy and liberty are raised if the request for ignorance is unheeded. It is acceptable for the patient to sacrifice his autonomy as an exercise of his liberty. The doctor restricts the patient's liberty by acting against the request not to know. Laurie[2] argues that the choice not to be informed turns on "psychological privacy which can be invaded by unwarranted disclosures of information."

The patient in this scenario has chosen to entrust the decision to his doctors. As they think it is the best option, so does he. This is consistent with a model of entrustment described by McKneally et al[3]after interviewing patients who had undergone major surgery. The patients in the study rejected the concept of weighing risks and benefits and other processes aimed to maximize their autonomy because they felt it was inappropriate to themselves as patients. They were also resigned to the risks of treatment, thought that "analyzing risks was irrelevant to their decision," and accepted the expert recommendation to consent to surgery. In essence, the patients in the study universally trusted "the competence and willingness of their surgeons to make good treatment decisions on their behalf."[3] Although this was a small study, the authors concluded that it was logical to apply the delegation of decision-making to another in the doctor-patient relationship.

The amount of information that should be disclosed to any patient to allow decision-making is debatable. If information about every risk is fully discussed, the patient may be overwhelmed and very alarmed, and may even lead to withdrawal of consent if fear impinges on the patient's ability to make a sensible and autonomous decision. Schwartz et al[4] write that "[p]atients can be said to have a right to any information they require to make a reasoned decision about their health." On this view, the patient in our scenario needs no further information because he has decided to have the operation regardless of the risks. Although his decision is not based directly on the balance of risks according to his personal values and higher order desires, there is certainly clear reasoning behind it.

The caveat here is whether his perception of the situation is correct. Does he understand that there is almost certainly only one realistic option, although the risks may be high?[5] In this case, it would appear he does. He intends to have operation anyway (reading between the lines he is resigned to it being the only option) and he knows that the risks are high because he believes disclosure would cause him and his family anxiety. This could be explored with the patient a little further as necessary by asking, for example, "do you think this is a major operation with serious risks?"

An alternative approach looks at the cognitive understanding of the operation and risks involved (accepting that certain risks may eventuate).[6] Cognitive understanding acknowledges that each patient will place differing worth or emphasis on each favourable or unfavorable outcome when weighing a decision, depending on individually held values. This is an area that can be useful to explore if a patient is having difficulty deciding whether to go ahead with surgery or which option to choose. By directly asking questions about what is important to the patient with each issue they are asked to consider, McCullough et al[6] state that the surgeon should "attempt to discern patterns of values in conversation with the patient" and that in this way may help "patients to connect otherwise unarticulated concerns." This will promote individual autonomy.[6]

Theoretically this is appealing, although in practice would be extremely time-consuming. It is also open to conscious or unconscious bias and possible manipulation by the surgeon, who will almost inevitably believe that surgery is the best option given that he has, by this stage, recommended it as the best or a reasonable option.

Furthermore, one of the cornerstones of autonomy is that it is individual, and even those who know us best and know our values cannot make decisions on our behalf that have equal autonomous weight with our own. This approach then falls back on acting in the best interests of those who cannot or will not make an autonomous decision. It is not, after all, an autonomy-promoting exercise but a deeper assessment of what may be in an individual's best interests. In a few cases, however, the discussion may promote autonomy in that the patient develops greater awareness of underlying values, but to suggest that this occurs regularly may be overly optimistic.

Does it help in this situation that the patient refuses to discuss the risks but agrees to the surgery? An attempt to assess the values he holds high may be of use in evaluating

whether his choice not to know is internally consistent with his higher order desires but helps little with the dilemma. If in the course of discussion the patient reveals that life on hemodialysis would be of very low value, one is the faced with the dilemma of whether to reveal this possibility as a risk. There may then be a moral duty to disclose this as a risk, but the question is difficult. A doctor cannot force a patient to listen, to do so may destroy the doctor-patient relationship and any attempt must be handled very sensitively. One approach may be to start with a general statement such as, "I think from talking to you that there is one particular risk you would wish to take into account," and proceed with disclosure, depending upon the patient's reaction. However, this is merely the surgeon's opinion of the patient's likely values and is similar to the surgeon acting in what he believes are the individual's best interests.

Option B directly breaches the patient's wishes and will clearly undermine the doctor-patient relationship. However, the main ethical concern here is breach of confidentiality, and such an option is difficult to justify ethically. Furthermore, any information gained is subjective. The family assessment of the patient's best interests may be a better guess than the surgeon's, but it cannot be a true representation of best interests and pales against the harm done to the doctor-patient relationship and the principle of confidentiality should this approach be adopted.

From the above arguments, option C is an ethically questionable approach. Many surgeons may be uncomfortable with nondisclosure of a real risk of death or serious life-affecting complications such as being rendered dialysis-dependent, but their discomfort is not at issue here. Option C is certainly an understandable choice but needs to be balanced against the patient's desire not to know. However, the argument that a real risk of death is so important as to be essential to consent holds particular weight in aneurysm surgery because most repairs are undertaken as prophylactic procedures to avoid death by rupture, rather than treat symptoms, so not to discuss risk of perioperative death is somewhat tautologous.

Option D sounds appealing, but is very difficult and time-consuming to implement and provides only subjective information as interpreted by the surgeon. Particularly given the inevitable surgical bias to operate when in a patient's best medical interests, the surgeon is unlikely to uncover values held by the patient that would convince him that not operating is a beneficient option and that he would be able to present in an unbiased manner to the patient. Any benefit that might possibly be gained would be minimal in most cases, and the surgeon's time might be better spent elsewhere (another ethical consideration!). This option may be of more value if a patient refuses and the surgeon believes this is genuinely not in the patient's best medical and personal interest and wishes to investigate further.

Option E seems unreasonable and ethically unnecessary, but one also has to take into account the doctor's personal and professional opinion. If he truly feels ethically unable to operate on this patient, he must ensure that the patient's medical care does not suffer and that he is swiftly referred to a willing colleague. The patient's refusal to discuss risks is not sufficient justification to withhold medically beneficial and potentially life-saving surgical intervention.

On the above arguments, option A has much merit as the patient has autonomously deferred the decision and understands in broad terms that this is a major operation and decision. Evidence suggests that even those patients who do accept risk disclosure in reality follow an "entrustment model"[3] rather than weighing the risks and reaching an autonomous decision with reference to their higher order desires and individual values. However, Katz's[7] caveat should be heeded: "[a] patient's waiver of the physician's obligation to disclose and obtain the patient's consent should be accepted only after a committed effort has been made to explore the underlying reasons for the patient's abdication of decision-making responsibility."

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